REHABILITATION MEDICINE Adding Life to Years

Sex and Disability Are Not Mutally Exclusive

Evaluation and Management

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Managing sexual problems in persons with disabilities is a team effort. Physicians have three special roles: identifying problems that are sexual; assessing these problems; and providing psychological, pharmacologic, or surgical treatment methods in the context of the patients' rehabilitation programs.

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Specific information about sexual activity patterns and sexual problems among persons with disabilities is fragmented and incomplete. Existing studies suggest, however, a major decrement in sexual activity in these patients. Humphrey found that only one couple in six remained sexually active after one partner had a cerebrovascular accident in the mid-50s.[1] The reasons given for this included the disruption of the normal rhythm of marital life, side effects of medications, depression in either partner, anxiety in the able partner, physical aversion for the disabled partner, and entrapment in a dependent role.

Almost half of a group of patients with multiple sclerosis indicated that they were sexually "less active" or "not active" since the diagnosis of their illness.[2] About half were concerned about their sexual situation. Men with multiple sclerosis indicated a high frequency of erection, ejaculation, and orgasmic dysfunctions; women indicated a decrease in sexual interest and changes in orgasmic responses.[3,4]

Less than 10% of men with complete injury to the spinal cord can ejaculate.[5] Neither men nor women with complete injury to the spinal cord experience genital orgasms.

More than half of disabled persons participating in a British survey reported that they were currently having problems with sex.[6] Of these respondents, 85% indicated that they would make use of sexual advice and counseling services. In a survey of men with spinal cord injury, 80% of respondents expressed a wish to use the informational or diagnostic services of a fertility clinic.[7] Of respondents to a Sex and Disability Project survey, 90% indicated that they would use sex education or counseling services.[8] In this survey, 64% of respondents expected physicians to provide sex education or counseling services, and 50% ranked the physician as the professional most expected to provide these services.

Physicians need a general strategy for assessing and managing the sexual problems of persons with physical disability.

Identifying Sexual Problems

Table 1 lists a number of functions that, in general, constitute the sexual areas in a person's daily life. Concerns in these areas come to a physician's attention in two ways: the complaints are clearly stated (direct presentation) or information about the problems is elicited by the physician.

Direct Presentation of 'Sexual' Complaints

A woman with multiple sclerosis says that since the last exacerbation of her condition, she has not been able to experience orgasms in intercourse or when masturbating. A man with cerebral palsy complains that he is unable to stimulate himself because he cannot hold his penis in his hands. A 62-year-old woman recovering from a stroke complains that intercourse is now painful. In each of these examples, the patient sought medical help for a "sexual" chief complaint. Sometimes the concerns are expressed through questions: A 32-year-old man with a recent spinal cord injury asked, "Will I be able to satisfy my partner? Will I be able to satisfy myself? Will I be able to have children?"

Eliciting Sexual Concerns

The Sex and Disability Project survey indicated that less than 5% of the respondents ever received sex education or counseling services.[8] Many patients are too shy or feel embarrassed to approach their physician with a sexual problem. "Have you any sexual concerns?" is a useful question. Asking a patient, "Do you have any concerns about your genital functioning?" may introduce a series of brief questions about each of the sexual areas listed in Table 1. An informative statement and a question, such as "Many persons with your disability report difficulties with some aspect of their sexual lives. What have been your experiences?" will help to elicit concerns under normal questioning.

Patients may not always be ready to discuss sexual concerns. For example, a physician asked a 19-year-old man with a recent injury to his spinal cord if perhaps he had concerns related to partnership or marriage. The young man said he had no worries in these areas. Several weeks later, however, this man approached the physician again and disclosed that he could not think of any lasting relationship unless it included intercourse. "How can I have intercourse if I don't have erections?" he demanded.

Conducting a Sexual Evaluation

A sexual assessment consists of a history, physical examination, and investigation. Some of the information may have to be supplied by the partner. An attendant may have to help with communication when the patient has a speech disorder. Assistance may be needed also with undressing and dressing before and after the physical examination.

History

The history begins with biographic information. Table 2 lists some of the important background items and their sexual significance. The chief sexual concern is clarified, and the person's functioning in each sexual area is briefly assessed.

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TABLE 1.—*Areas of Sexual Function and Related Problems*

Area	*Expected Functions*	*Problems*
Sexual response	Genital sensation	Altered, absent
	In men	
	Erection	Partial or no erection
	Ejaculation	Delayed, retrograde, absent
	Orgasmic sensation	Delayed, reduced, absent
	In women	
	Lubrication	Diminished, absent
	Vaginal accommodation	Reduced, pain on intercourse
	Orgasmic sensation	Delayed, reduced, absent
Fertility	In men	
	Ejaculation	Retrograde, absent
	Motile spermatozoa	Reduced number, absent
	In women	Physical aspects of pregnancy
Motor functions	Hugging, holding, and other "sex" acts	Unable or lacking skills to carry out "sex" acts
Urinary, bowel, or gas control	Continent during "sex"	Incontinent, wearing stomal pouches, odors
Partnership	Finding partners, maintaining partnership	Inadequate social and courting skills
	Engaging in sex acts	Inadequate or inappropriate "etiquette"
Sexual self-view	Perception of one's "sex appeal"	Anxiety about "performance"
Sexual interest	Desire or motivation for sexual experiences	Reduced, or lack of, interest

The identified symptoms then need to be classified with regard to the duration and circumstance of their occurrence. In terms of duration, the physician needs to find out if the problem is primary, that is, a life-long complaint, or secondary, that is, a relatively recent but persistent complaint that followed a specific event, such as the start of the disability.

In searching for the cause of symptoms in the sexual response area, a physician should keep two principles in mind. First, impairments in genital functioning may or may not be connected to the major disability. A man with spinal cord degeneration said that he was "unable to have intercourse." This inability was first interpreted as an erectile dysfunction secondary to the disability. A more careful review, however, quickly pinpointed the problem: Peyronie's disease (unrelated to the spinal cord degeneration) caused an acute-angle deformity of the man's penis when in the erect state, making intercourse virtually impossible for him.

A 38-year-old woman said that since the onset of her multiple sclerosis, intercourse had become painful. Her problem was first explained as a lack of vaginal lubrication because of her sexual disinterest that in turn was thought to be due to the tiredness associated with her disease. A clarifying history, however, revealed that her pain was only experienced on deep thrusts of the penis. In addition, the woman insisted that her sexual interest had not changed; she merely wished to avoid the painful experiences. A physical examination and ultrasound studies showed a large ovarian cyst that was responsible for the pain on deep thrusting.

A careful history may differentiate between an impairment in genital functioning and a situational dysfunction. In the latter case, a mental state sets in so that a situation generally thought of as "sexual" is reduced to a nonsexual event and hence the person may not experience the expected genital response. A few such nonresponses may be interpreted as failures, which may lead to strong anxieties about the next performance. The anxieties then may precipitate the situational dysfunction. A patient prone to performance anxieties may forewarn the physician of these anxieties by making such comments as, "To me, sex means the act of intercourse . . . oral stimulation or genital stimulation with the hand is foreplay only," or "If I cannot finish because my erection does not last, I don't even want to start it."

Assessing fertility potential. Regular menstrual periods are the best clue to a woman's fertility status. In men, semen analysis is the first step in the assessment. If there is no ejaculation but there is orgasm, retrograde ejaculation must be suspected. The first 20 ml of a postorgasmic urine specimen usually contains the ejaculate.

It is more difficult to assess a person's desire to become a parent. Some persons with severe disability show an overwhelming preoccupation with the issue of parenthood. Assessment questions may need to be aimed at discovering how the couple visualize themselves during the period of pregnancy, birth, the postnatal period, and the first few years of child rearing. Genetic heritage may need to be explored. The intention of all the questions is not to dissuade but to clarify.

Assessing the other sexual function areas. A physician should first try to find out a patient's physical and social

TABLE 2.—*Importance of Background Information*

Item	*Significance of Information*
Age	Advancing age may adversely influence sexual practices
Partnership status	Explains context in which person lives and wants sexual fulfillment
Occupation and education	May indicate person's ability to handle information
Children	Indicates past reproductive and parenting capability
Religious beliefs	May forewarn regarding perspectives to be aware of
Mood levels	Reflects on mental state, may forewarn depression
Nature of the disability	
Congenital	Often implies sheltered life-style
Acquired after puberty	Past partnership and sexual experience likely
Progressive	Recurrent hospital admissions, tiredness
Medical condition	Defines health status; progressive disorders may adversely influence sexual activity
Medications	May have adverse effect on sexual physiology
Past sex practices	Varied and satisfying past practices may be the basis of a future sexual life
Energy level	Sexual interest often depends on energy
Timing of the visit—	
Why now?	Certain favorable or untoward life events may have occurred recently

TABLE 3.—*Assessing Areas of Sexual Function*

Sexual Function Area	*Relevant Observations and Questions*
Motor functioning capability	Mobility, transfer from wheelchair; ability to dress independently, manual dexterity; hip adduction and knee flexion
Genitourinary and bowel control	Odors, appearance, and cleanliness of stoma bags, urinary conduction devices, leg bags, and catheters
Menstrual control	Extent and regularity of menstrual flow; manual dexterity for inserting tampons
Sexual behavior and partnership	Language skills and social conduct; past partnerships—ages, duration, and depths of relationship; skills of meeting and breaking off; extent of sexual experiences—preference for solitary or homosexual acts
Sexual self-view	Gender identification; manner of dressing, hairdo, makeup, concepts of manliness and womanlinesss, perceived manliness and womanliness, perceived sex appeal and attractiveness
Sexual interest	Compare past and present practice frequencies; efforts made to socialize, efforts made to read sex-oriented books or see sex-oriented movies; dreams and fantasies with sexual content

requirements for finding a partner, maintaining a relationship, creating a private environment, maintaining genital hygiene, or entering into the physical acts of intimate contact and then inquire about the patient's functioning capacity in these areas (Table 3).

Physical Examination

The physician needs to find out a person's physical capabilities as they relate to sexual situations—dressing and undressing, transferring from wheelchair to bed, moving about in a sex act. The general hygiene and cleanliness in the genital area, including the state of stomas and urinary conducting devices, and the structural and neurologic integrity of the genitalia should be assessed.

The first two points can be clarified by observing the patient's way of getting around and by inspecting the genitalia. In men, the genital examination can be done while the patient is in the wheelchair. A pelvic and rectal examination in a person with severe disability may require special arrangements in an outpatient department, where the transfer from a wheelchair to a special examining table might be accomplished more easily and where staff may be available for assisting with leg positioning and the management of leg spasm. Unfortunately, there are no reliable physical tests to show the capability of erection. In men with spinal cord injury above the sacral neurologic levels, physical touch to the penis may cause a reflex erection. Sometimes these erections prove to be sufficient for the act of intercourse, but often they last for only a few seconds. If there is evidence of a low spinal cord lesion and a squeeze of the testicles produces pain, erection in response to mental stimulation may be possible. These penile reactions are often insufficient for intercourse.

The potential for orgasmic responses in men and women with neurologic lesions is usually confirmed when patients correctly identify a pinprick sensation on the glans penis and in the clitoral area and are able to contract the anal sphincters voluntarily (or "wiggle" the penis and contract the vaginal os). The former test confirms the integrity of the lateral spinothalamic tracts, the latter that of the continuity of the pyramidal tract system. These two spinal cord tracts seem to be essential for the occurrence of orgasmic reactions.

Investigations

The simplest way to investigate sexual problems is to ask people to experiment privately and then report their findings.

Measuring nocturnal penile tumescence may be of value when information from the history is insufficient to differentiate between a situational (psychological) and a global (organic) erectile dysfunction.[9] A satisfactory response to an intracavernous injection of papaverine hydrochloride or prostaglandin E_1 usually eliminates a vascular cause in a patient with erectile dysfunction. An unsatisfactory response to even higher dosages of these medications suggests a vascular origin requiring further investigations.

Urodynamic tests may be useful for estimating the integrity of the urinary system and, indirectly, the neurologic integrity of the erectile or ejaculatory responses.

Laboratory tests may include serum testosterone levels and sex hormone-binding globulin ratios in men, estrogen and progesterone levels in women, and luteinizing hormone, follicle-stimulating hormone, and prolactin levels in both.

Providing Care

One consideration in treatment is that a patient is not a "disabled" entity but a person who has a desire for adequate interpersonal and sexual functions and who happens to have certain disabilities. The other is that the management of sexual problems may be incomplete without attention to the patient's psychological, social, and vocational rehabilitation.

Direct and Indirect Care

Direct care may include listening to a person with a sexual concern, giving information about sex physiology or practices, offering suggestions about adapting physical activity techniques of daily living to the physical demands of intimate physical contact, and providing in-depth management.

Indirect care may consist of providing opportunities for privacy and making arrangements for social occasions and the needed transportation. Physicians and other health or social care professionals, partners, and friends, regardless of role or job title, can provide many aspects of indirect sexual health care. The facilitation of social skills, such as language skill management and improving appearance through appropriate dressing, hair care, or cosmetics, is important.

Most persons with disability and a sexual problem expect a physician to assist with concerns related to genital functioning, fertility, and dilemmas in selecting the appropriate birth-control method.

Treatment of Sexual Response Problems

Talk-oriented methods. Sex therapy was originally designed for nondisabled, highly motivated couples when one or both partners suffered from psychologically based erection and ejaculation problems in men and orgasmic problems and pain on intercourse in women. An advantage of this technique, however, is that it can be applied in steps. For example, in couples for whom intercourse is not a realistic possibility either because of physical limitations or because of impairments of genital functioning, specific suggestions can be offered about experiencing erotic pleasure without concern for erection, erection without orgasm, extravaginal orgasm, or intromission without orgasm.[10] Persons with spinal cord injury, for example, often report pleasurable sensory

experiences arising out of caressing the ear, neck, or other areas of the body where sensory perception has been spared.

Pharmacologic methods. Intracavernous self-injections of papaverine hydrochloride, papaverine and phentolamine mesylate, or prostaglandin E_1 may assist erectile problems. An evaluation of the short-term and long-term consequences of this method may be found elsewhere.[11,12] Patients must have either a reasonable degree of eye-hand coordination and manual dexterity to self-administer the injections or a partner who is willing to give the injections. Persons with neurologic impairment of the erection process are particularly prone to medication-induced priapism and require a considerably smaller dose than do others. Women in their postmenopausal years may require hormone supplementation to prevent pain on intercourse.

Surgical methods. Penile prosthesis implantation may be of value for men with organic erectile dysfunction. This approach, however, in addition to its recognized disadvantages, may impose further problems on a person with spinal cord injury. The prosthetic device may cause pressure sores in men with neurologic injury. Hand dexterity is required to activate some of the devices. Use of the device may interfere with urinating.

Assisting with physical methods. Intimacy does not require sexual intercourse. Virtually no disability precludes some form of physical closeness in bed. A partner may assume responsibility for body positioning. The loss of arm, hand, or finger dexterity may be compensated for by the mouth. A vibrator may be useful in self or partner stimulation. Physiotherapy techniques used to improve capabilities for performing activities of daily living can be used to improve the ability for sex practices.[13] External prosthetic devices may provide a noninvasive method of inducing erection. Some of these devices are condom-shaped and use a vacuum principle to stay on a flaccid penis. This method may be of additional value to persons who are concerned about urinary incontinence during intercourse. Other vacuum principle-based devices use a strong rubber band to hold the venous congestion in the penis.

Treatment of Fertility and Birth Control Issues

New techniques are becoming available for procuring sperm. This is particularly important for younger persons with spinal cord damage who have neurologic impairment of the ejaculation mechanism. Vibratory stimulation of the penis and electroejaculation techniques are proving to be the two most useful methods when followed by artificial insemination procedures.[14,15] Many men with severe disability are able to ejaculate but may not be able to perform the act of intercourse. Their ejaculate may be collected in a nonspermicidal condom and transferred into the vagina by a physician or at home by the nondisabled partner. Persons with certain disabilities may require genetic counseling before considering fertilization procedures.

Most birth-control methods pose disadvantages to persons with a disability. Each method needs to be thought of as either active (for example, putting on condoms, inserting a diaphragm) or passive (for example, using an intrauterine device, taking birth-control pills, or having a vasectomy or tubal ligation).[16] The active methods require a certain degree of motor coordination. Of the passive methods, an intrauterine device may be troublesome to women with sensory deficiencies because they may not be able to feel symptoms of uterine perforation. Birth-control medication may be contraindicated for women in wheelchairs, who may have a predisposition for thrombophlebitis.

Managing menstrual hygiene in women with severe disability may require suppressing ovulation or doing a hysterectomy. Women with disabilities must have a clear understanding of the implications of a hysterectomy.

Outcome of Care

The complexity, urgency, depth, and variety of needs, goals, and experiences in the sexual areas are highly personal and may vary with such factors as age, gender, physical ability, or health status. Two persons with a seemingly similar disability and about the same medical approach to their sexual problems may end up with different results. My experience with persons with spinal cord injury suggests that, regardless of the severity of the disability, the prognosis is good for reestablishing or creating a satisfactory (although perhaps different) sexual life-style when patients' past sexual experiences were varied and satisfying and when there exists a relationship with a sexually interested and interesting partner.[17] The physician's inquiry and appropriate assessment confirm a patient's manhood or womanhood. This confirmation seems to be an important component of the rehabilitation process.

Summary

The key to a physician's success in assessing and treating sexual problems is comfort in asking relevant questions. In turn, comfort comes from two sources: accepting disabled patients as persons, who happen to have certain disabilities and whose sexual needs, goals, and experiences are similar to those of the seemingly nondisabled; and using a framework to guide an objective assessment. Once the needs and goals are clarified, decisions can be made rationally about providing the appropriate medical assistance.

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